Giving Chronic Pain a Medical Platform of Its Own

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Most doctors view pain as a symptom of an underlying problem — treat the disease or the injury, and the pain goes away.

But for large numbers of patients, the pain never goes away. In a sweeping review issued last month, the Institute of Medicine — the medical branch of the National Academy of Sciences — estimated that chronic pain afflicts 116 million Americans, far more than previously believed.

The toll documented in the report is staggering. Childbirth, for example, is a common source of chronic pain: The institute found that 18 percent of women who have Caesarean deliveries and 10 percent who have vaginal deliveries report still being in pain a year later.

Ten percent to 50 percent of surgical patients who have pain after surgery go on to develop chronic pain, depending on the procedure, and for as many as 10 percent of those patients, the chronic postoperative pain is severe. (About 1 in 4 Americans suffer from frequent lower back pain.)

The risk of suicide is high among chronic pain patients. Two studies found that about 5 percent of those with musculoskeletal pain had tried to kill themselves; among patients with chronic abdominal pain, the number was 14 percent.

“Before, we didn’t have good data on what is the burden of pain in our society,” said Dr. Sean Mackey, chief of pain management at the Stanford School of Medicine and a member of the committee that produced the report. “The number of people is more than diabetes, heart disease and cancer combined.”

For patients, acknowledgment of the problem from the prestigious Institute of Medicine is a seminal event. Chronic pain often goes untreated because most doctors haven’t been trained to understand it. And it is isolating: Family members and friends may lose patience with the constant complaints of pain sufferers. Doctors tend to throw up their hands, referring patients for psychotherapy or dismissing them as drug seekers trying to get opioids.

“Most people with chronic pain are still being treated as if pain is a symptom of an underlying problem,” said Melanie Thernstrom, a chronic pain sufferer from Vancouver, Wash., who wrote “The Pain Chronicles: Cures, Myths, Mysteries, Prayers, Diaries, Brain Scans, Healing and the Science of Suffering” (Farrar, Straus & Giroux, 2010) and was a patient representative on the committee.

“If the doctor can’t figure out what the underlying problem is,” she went on, “then the pain is not
treated, it’s dismissed and the patient falls down the rabbit hole.”

Among the important findings in the Institute of Medicine report is that chronic pain often outlasts the original illness or injury, causing changes in the nervous system that worsen over time. Doctors often cannot find an underlying cause because there isn’t one. Chronic pain becomes its own disease.

“When pain becomes chronic, when it becomes persistent even after the tissue and injury have healed, then people are suffering from chronic pain,” Dr. Mackey said. “We’re finding that there are significant changes in the central nervous system and spinal cord that cause pain to become amplified and persistent even after the injury has gone away.”

The institute emphasized the importance of prevention and early treatment, a novel concept for many doctors who try to diagnose the source of pain before treating it or advise patients to wait it out in the hope it will go away on its own.

“Having pain that is not treated is like having diabetes that’s not treated,” said Ms. Thernstrom, who suffers from spinal stenosis and a form of arthritis in the neck. “It gets worse over time.”

Ms. Thernstrom compared the effect of chronic pain on the body to the rushing waters of a river carving out a new tributary. Pain, she says, also changes the body’s landscape.

“My pain is at the level where it’s manageable,” she said. “I do wish I had gotten aggressive treatment in the first year. There is a window of time to intervene, because pain changes your nervous system and pain pathways develop.”

The report also acknowledged the “conundrum of opioids,” noting that doctors are conflicted about how to treat pain because of worries about drug addiction. But the group noted that proper use of the drugs early in a pain cycle can resolve pain problems sooner, and stated that opioids are also particularly useful for pain management near the end of life.

The pain report is only a first step for the community of medical professionals who treat pain. It will be up to medical schools to begin better education of doctors in the treatment of pain, and the National Institutes of Health to decide whether to promote research into chronic pain. Patients, too, need to be educated about the importance of early treatment of pain rather than gutting it out or waiting until it has become severe and chronic.

“Some people were expecting a cure within the report,” Dr. Mackey said. “There’s no immediate cure. But I’ve seen a lot of patients who have said, ‘Finally they are putting out a report that helps others understand what I’m going through.’ ”